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# More than the money: A review of the literature examining healthy volunteer motivations

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## **Abstract**

**Background and Objective**—Few existing data report the motivations of healthy volunteers in clinical research trials. Some worry that volunteers consider only financial motivations. This study summarized and analyzed existing empirical research on self-reported motivations of healthy volunteers participating in studies not intended to offer benefit from participation.

**Study Selection**—A systematic PubMed search was conducted. Inclusion criteria captured English-language empirical studies on the self-reported motivations, reasons, or factors influencing the decision of healthy volunteers to enroll in clinical research. Twelve studies involving more than 2000 healthy volunteers met the criteria and were included in this review.

**Data Extraction**—Independent review by the authors and extraction of information about the sample, methodology and objective of the motivations study, description of the clinical trial and whether participation was actual or hypothetical, reported primary and secondary motivations of the healthy volunteers, risk evaluation, and reported differences in motivations related to sociodemographic variables.

**Results**—This review showed that although financial reward is the primary motivation for healthy volunteers to participate in clinical trials, financial motivations are one among many other reported motivations, including contributing to science or the health of others, accessing ancillary healthcare benefits, scientific interest or interest in the goals of the study, as well as meeting people and curiosity. Volunteers consider risk when making a decision about participation.

**Conclusions**—Although financial incentives are important in recruiting healthy volunteers, their motivations are not limited to financial motivations. Further research is needed to examine

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motivations in different contexts and countries, the decision making of healthy volunteers, and the dynamics of repeat participation.

# Keywords

Motivations; Human Subjects; Clinical Trials

# INTRODUCTION

Healthy volunteers for drug development trials and other research are exposed to risk and discomfort without any expectation of health benefits. These volunteers are essential to the development of new drugs and biologics and for testing new formulations, and invaluable for investigating drug safety, dosing, and pharmacokinetics. However, few have examined why healthy individuals volunteer to participate in research. While clinical research participants who suffer from disease are often motivated to participate in research in order to gain possible therapeutic benefits and free medical treatment, or to help fight or better understand the disease that afflicts them, <sup>1-4</sup> the motivations of healthy research participants are likely to be quite different. The widespread perception is that healthy volunteers who enroll in clinical research are motivated strictly by financial reward. <sup>5, 6</sup> For instance, Carl Elliot asserts: "the relationship between testers and test subjects has become, more nakedly than ever, a business transaction." To the extent this is true, several ethical issues arise. Some commentators have suggested that volunteers who are only motivated by payment disregard risks or may not be able to properly assess the risk of a particular study. 8 Others worry that payment for research participation disproportionally attracts low income volunteers, and thus result in research that disproportionately burdens the poor.<sup>8-12</sup> Empirical evidence that supports these concerns is limited. Further, financial motivations do not necessarily preclude other motivations or considerations.

Currently, no systematic review of the literature examines research on healthy volunteer motivations. In this paper, we examine, classify and compare empirical studies which measure self-reported motivations, reasons for participation, and/or decision making processes for healthy volunteers participating in drug studies and other clinical research not intended to offer health benefit from participation.

# **METHODS**

# Systematic Review

A comprehensive PubMed search limited to English language only used a combination of Medical Subject Heading (MeSH) terms and keywords reflecting three search criteria (Figure 1): human subjects research, motivations or reasons for participation in research, and decision making by healthy volunteers rather than patients or physicians. The MeSH term "Empirical Research" or "Biomedical Research" fulfilled the first criterion, human subjects research. MeSH terms "Motivations" or "Decision Making" and the keywords "characteristics," "why," "willingness," or "motivations" in the title or abstract fulfilled the second criterion, focusing on motivations or reasons for participation in research. The third criterion, decision making by the volunteer, required the MeSH term "Research Subjects," or

the keywords "volunteer," "human subject," or "participant" in the title, or the words "healthy subject" or "normal subject" in the title or abstract. Positive motivations were defined as those motivations which influenced a volunteer to participate, as opposed to barriers or burdens, which influence a volunteer *not* to participate in research.

The initial PubMed search yielded 2015 publications as of March 26, 2010. Studies were excluded which asked participants whether or not they would be willing to consider participation in various hypothetical research scenarios without asking them to report motivations for participation. Also excluded were studies of patient volunteers, studies of volunteers who cannot consent, and volunteers in lifestyle intervention, vaccine, or prevention studies. Although these latter groups include healthy volunteers, they often perceive a possibility of health benefits from the lifestyle, prevention or vaccine intervention itself, and thus their motivations differ from healthy volunteers participating in drug development trials. A total of 12 studies involving more than 2000 healthy volunteers were included in this review- eight were identified through criteria applied in the PubMed search and four additional studies identified through hand search and examination of papers cited by those included.

# **Data Analysis**

Each author reviewed identified studies and extracted information about the clinical trials and the motivations studies. Sample characteristics extracted from the published studies include the number and type of subjects, the type and location of clinical trial(s) in which subjects were volunteers, whether qualitative or quantitative methods were used to measure motivations, and whether motivations were investigated as part of an actual clinical trial or in response to one or more hypothetical studies. Data were extracted about the methodology and objective of the motivations study, reported primary and secondary motivations of the healthy volunteers, information related to repeat volunteers, risk evaluation, and differences in motivations due to sociodemographic characteristics.

Direct comparison or meta-analysis of study data was not feasible, as there was no uniform methodology or study design employed by the relevant studies. Using the database and careful review of the papers, qualitative themes were developed and analyzed.

# **RESULTS**

Of the twelve <sup>13-24</sup> studies identified, six were conducted in the United States, <sup>15-17</sup>, <sup>19</sup>, <sup>22</sup>, <sup>24</sup> five in Europe, <sup>13</sup>, <sup>14</sup>, <sup>20</sup>, <sup>21</sup>, <sup>23</sup> and one in Malawi. <sup>18</sup> The Mtunthama study, which took place in Malawi, was the only published research on this topic from a developing country identified by our review. Each of the twelve studies used quantitative methods to describe and compare different motivations; three studies also included qualitative components. <sup>17</sup>, <sup>18</sup>, <sup>22</sup> Eight studies involved healthy volunteers who had actually participated in clinical trials, <sup>13-18</sup>, <sup>20</sup>, <sup>21</sup> two studies asked participants about why they might be motivated to participate in a hypothetical study, and two measured both motivations to join an actual and a hypothetical trial (Table 1)<sup>14</sup>, <sup>15</sup>, <sup>19</sup>, <sup>22</sup>. Overall, more than 2000 healthy volunteers were included in the reviewed studies. In all of the actual and hypothetical studies volunteers received or were informed they would receive financial compensation.

There were a range of study objectives, including comparing motivations among subpopulations of volunteers, identifying motivations and barriers for recruitment, and assessing the weight of financial compensation. Ten of the twelve studies had a questionnaire component. <sup>13-16</sup>, <sup>19-24</sup> Eight of these assessed motivations using multiple choice questions, <sup>14</sup>, <sup>15</sup>, <sup>19</sup>, <sup>20</sup>, <sup>22-24</sup>, two asked volunteers to numerically rate motivators. <sup>13</sup>, <sup>21</sup> Four of the twelve studies had an interview component. <sup>16-18</sup>, <sup>22</sup>

Financial reward was one of the main motivations for study participation identified in eleven of the twelve studies <sup>13-17, 19-24</sup> and was the principal reason for participation reported in eight studies. <sup>13-16, 21-24</sup> Access to healthcare was the main reported motivation in the Mtunthama study, <sup>18</sup> as well as the main incentive for the elderly volunteers studied by van Gelderen et al. <sup>20</sup> Helping to contribute to science and medicine, <sup>13, 15, 19, 21, 23</sup> helping others, <sup>15-17, 19-23</sup> meeting people, <sup>17</sup> relaxing <sup>17</sup> or wanting to participate in something important, <sup>19</sup> learning more about science and medicine, <sup>14, 16, 17</sup> and curiosity <sup>13, 14, 16, 18, 19</sup> were other reported motivations for participation (Table 2, Table 4).

Qualitative analysis revealed five themes related to reported motivations of healthy volunteers: complex motivations, risk, repeat volunteers, ancillary care, and a personal approach.

## THEMES

# **Complex Motivations**

Although not the sole motivation for all participants in any of the studies, financial reward, as noted above, was one of the main motivations for participation in eleven of twelve studies, <sup>13-17, 19-24</sup> and the principal motivation in eight of the twelve studies. <sup>13-16, 21-24</sup> In fact, one of the volunteers interviewed by Kass et al. made it clear that money is necessary to incentivize research with healthy volunteers: "Money is what motivated your studies, not Robin Hood doing good for people and all that". <sup>17</sup> In that study, 55% said that money was a good aspect and 46% said money was the best aspect of participating. In the one study in which payment was not identified as the principal motivation for participation, no subject declined the offer of payment, and 6 of the 81 volunteers stated they were motivated in part by money. <sup>18</sup>

Walsh and Nash, surveying both research volunteers and people who had not volunteered, found that "nonvolunteers" were less likely to cite financial motivations as a reason to participate in research than actual volunteers (52% versus 81% respectively).<sup>22</sup> This may suggest that while prospective volunteers may have multiple motivations, it is the offer of money that pushes people to actually volunteer. However, Cunny and Miller found the opposite result: "nonvolunteers" were *more* likely to cite financial motivations than actual volunteers (92.6% versus 85.1% respectively),<sup>15</sup> suggesting that volunteers are influenced by motivations aside from money. Cunny and Miller advised investigators to provide adequate compensation in order to avoid recruitment difficulties.

However, in no study were financial rewards the sole motivation for participation, as noted above. In fact, some volunteers expressed a willingness to consider volunteering with no

financial compensation. In the Vrhovac study, for example, 20.6% of volunteers denied that financial reward was their only motivation, 21 and cited humanitarian reasons and contributions to society as important. Almeida et al. found that 8.8% of volunteers were willing to volunteer without financial rewards, and 52.9% were willing to consider it. Only 4.2% of the medical students surveyed in Bigorra and Baños' study said they would participate for financial reward alone; the rest said they would participate because of scientific interest or a combination of scientific interest and money. 14 Similarly, Kass et al. found that while a few volunteers mentioned money as the sole motivator, most mentioned money as one among several reasons they volunteered. <sup>17</sup> Only 6 of 81 participants in the Mtunthama study reported money as their motivation, instead, most volunteers reported participating to gain access to health care. 18 Hermann et al. found that while 53% of volunteers said their main motivation was money, many had secondary social motivations many saw studies as a good way to meet people and make friends.<sup>23</sup> While money may be necessary to attract healthy research volunteers to participate in studies, healthy volunteer motivations are not simple or one-dimensional. Instead, these studies suggest that although money might interest healthy volunteers in seeking information about study participation, there are other important factors involved in motivating volunteers to enroll or remain in research.

The relative importance of financial motivations also appears to differ among groups of volunteers. In the Almeida study, for example, volunteers with low income and education levels valued money more than other volunteers, while high income volunteers were more likely to consider participating in the absence of financial incentives. <sup>13</sup> In contrast, Kass et al. found that white, college graduates in their study were actually more likely to mention money as a reason for participation. <sup>17</sup> Van Gelderen et al. found that younger volunteers (18-30 years-old) were more likely to cite money as a reason for participation than older volunteers. <sup>20</sup> Novak et al. found that older inmates in their study were more likely to cite money as a motivation than students and employees. <sup>19</sup> Age, education, and social circumstances appear to have an influence on how important money is as a motivating factor for research participation. More research is needed in this area.

Perceptions of and opinions about the role of money also differed among groups. Most volunteers in Bigorra and Baños' study (82.5%) considered payment as compensation for the time and discomfort of research participation. While most (84.5%) in the Vrhovac study thought that they should be paid in proportion to time spent in the trial, 75.3% thought payment should be proportionate to the severity of the potential adverse drug reactions they were at risk of suffering and 82.5% said payment should be increased when blood samples were taken. <sup>21</sup>

Studies that probed volunteers' opinions about the amount of reward they received found that most, but not all, were satisfied with the amounts offered for participation. Almeida et al. found that most volunteers (63%) considered the amount sufficient; 34% considered it good; only 4% considered it low.<sup>13</sup> Bigorra and Baños, found that 12.5% of volunteers considered the payment low; 83.7% considered it adequate, and fewer, but still more than half (53.7%) considered it to be "well balanced for inconvenience and for the perceived risk." Surprisingly, 3.8% considered the compensation high. In proportion to the expected

risk, most (90%) found the compensation adequate. <sup>14</sup> Most (81%) volunteers in the van Gelderen study considered the payment reasonable compensation, while 12% considered it unreasonable. However, of those who participated primarily because of the money, an even greater percentage (87%) considered the monetary compensation reasonable. <sup>20</sup> Few volunteers reported inadequate compensation: in the Mtunthama study, 7 of the 81 volunteers indicated that the payment offered was inadequate, <sup>18</sup> and in the Kass study, 3 out of 60 cited "too little pay" as a bad thing about studies. <sup>17</sup>

## Risk

Even volunteers motivated primarily by the prospect of financial reward reported that risk was an important limit on research participation. Many volunteers reported risk as an important factor and some said there was an "absolute limit" on the risk they were willing to accept. For example, Hassar et al. found that volunteers tried to evaluate the risk of the study before making a decision about participation, and that the risk of the study was the ultimate deciding factor for the volunteers they surveyed.<sup>16</sup>

Studies that included individuals who chose not to volunteer reported that concern about risk was the major reason for declining (45.6% in one study, and 53% in the other). <sup>15, 19</sup> Almeida et al. reported that most volunteers (80%) who had sought advice from family, friends, or their physicians were advised not to participate, in many cases because of the perceived risk of the study. <sup>13</sup> However, all of these volunteers had decided to participate anyway, and very few (2.2%) ultimately felt worried about risk once the study began. Similarly, only 1 out of 5 volunteers interviewed by Kass et al. mentioned risk during the interview. <sup>17</sup> These data suggest that volunteers who decide to participate have decided that the risks of participating are acceptable after acknowledging and considering these risks.

### **Repeat Volunteers**

Repeat volunteers were more likely than others to be motivated by financial reward. Bigorra and Baños report that 90% of repeat volunteers listed financial reward as a primary motivation, while only 33.1% of medical students who were not experienced volunteers chose financial reward as a primary reason for volunteering. Similarly, Hassar et al. found that after the first study, the volunteers surveyed in a university setting were motivated to participate in further studies because of financial reward.

Other commentators worry that individuals with lower income and lower education are more likely to be repeat volunteers, and are thus at risk of being unfairly burdened or even exploited in research. 11, 25, 26 Kass et al. found that volunteers who had participated in more than 10 studies were less likely to have a college degree than other volunteers, 17 lending some credence to these worries. More research to identify the sociodemographic characteristics and decision making of repeat participants is needed, as is further analysis of the extent to which repeat participation is a burden or a welcome source of income.

# **Ancillary Care**

In countries with less developed health care systems or for people with limited access to health care, ancillary care may be as alluring as cash. In the Mtunthama study of volunteers

participating in bronchoscopy studies in Malawi, 75 of 81 reported that their main motivation was to gain access to a health assessment, and 61 to gain more timely access to treatment when ill. <sup>18</sup> Two European studies also showed that ancillary care benefits were an important motivator. Of the volunteers in the van Gelderen study who reported that they participated for a free check-up, 75% were over 60 years old. <sup>20</sup> Almeida et al. also found that a free medical check-up was a highly rated reason for volunteers, although it was not as highly rated as financial remuneration. <sup>13</sup> None of the U.S. studies reported access to ancillary care as a motivation for participation.

# A Personal Approach

Although not reported as a motivation per se, a personal approach to recruitment and dealing with research volunteers was discussed by volunteers in several studies. A personal approach can mean several things, including acknowledging volunteers' time commitment and sacrifice by arranging research participation around their schedule, responding appropriately to pain and discomfort, sharing research results with volunteers, positive and friendly interactions among research volunteers and between volunteers and staff. Personal contact with staff and fellow volunteers was the most pleasant part of study participation reported by 30% of the volunteers in the van Gelderen study. <sup>20</sup> Similarly, Kass et al. found that volunteers' experience was significantly influenced by their perception of how staff treated them; they named lack of staff attention to adverse effects as a bad aspect of research participation.<sup>17</sup> Mtunthama et al. found that volunteers were very interested in learning the results of the research. <sup>18</sup> These issues may have a significant impact on study recruitment, as 94.9% of volunteers surveyed by Almeida et al. reported that they had heard about the trial by word-of-mouth. 13 Herman et al. reported that volunteers consider staff behavior, their relationship with other volunteers, and other aspects of the study environment to have a large impact on their well-being while participating in the study.<sup>23</sup> A personal approach to recruitment and interacting with research volunteers may have an effect on recruiting repeat volunteers, and could even have an impact on recruitment of naïve volunteers, especially if word-of-mouth is a major source of information about research projects. This facet of volunteers' experiences may influence decision making and have an impact on overall interest in research participation, enrollment, and retention of volunteers.

# **FURTHER DISCUSSION**

Although commentators speculate about how financial motivations affect healthy research volunteers, there are few empirical studies on healthy volunteer motivations. Commentators denounce payment as leading to risk distortion, a disproportionate research burden for the poor, and destruction of altruistic motivations for research participation, because payment is assumed to be an all consuming motivator. The twelve identified studies reviewed here which focused on the positive motivations of more than 2000 healthy research volunteers showed that healthy volunteer motivations cannot be succinctly described as only for the "money." There is a clear need for more research to inform judgments about the ethics of payment and enrollment of healthy research volunteers.

While money appears to be the primary motivation for healthy research volunteers, the majority of volunteers weigh other considerations. A recent qualitative study of healthy volunteer experiences similarly found that most healthy research volunteers, although initially attracted by the prospect of making money, carefully "shop" among available studies to select those which they find acceptable.<sup>27</sup> Our current review of empirical studies shows that healthy volunteers consider research participation because of the prospect of financial reward, but then weigh a range of concerns including risks, inconvenience, study goals, possible health benefits, the prospect of meeting new people, the possibility of contributing to society, and learning about the scientific process. Being attracted to research participation because of money does not necessarily mean that volunteers make risky or poorly-informed decisions. While some worry that financial considerations might eclipse other considerations such as risk, existing data summarized in this review do not appear to support this worry.

In a similar vein, commentators have concerns that offers of payment might impair research volunteers' assessment of risk. 8, 28 The studies identified by this review suggest that instead of ignoring risks, many volunteers acknowledged and considered the possible risks of the study, some individuals even declined because of risk. Many had been cautioned by friends and family about risk. Rather than overlooking risk, risk was reported as an important consideration in their research participation decisions. More research on perceptions of risk among healthy volunteers, how risk influences decision making, and what the risks actually are would be very valuable.

Some worry that volunteers who participate repeatedly are more likely to discount risks or to be motivated solely by financial considerations.<sup>26</sup> Data from these empirical studies do not directly refute nor validate this worry. The few studies that examined repeat volunteers suggest that these volunteers are motivated by money at a higher rate than naïve volunteers, yet more research is needed to examine how repeat participation influences evaluation of risks.

### Limitations

Although only twelve published studies have measured the self-reported motivations of healthy volunteers who participate in drug development and other studies of no benefit to them, together they report motivations on more than 2000 healthy volunteers. Comparison of these published studies is limited because of diverse methodologies and measures, small sample sizes, and limitations specific to individual studies. The conclusions from this summary of the current literature should be used to inform future research about healthy research volunteers' motivations and decision making.

In addition, in all reviewed studies conclusions rely on volunteers' assessment and reporting of their own motivations for participation. Other studies in the literature examine individuals' willingness to participate in various research scenarios and attempt to draw conclusions about what factors within those scenarios are driving volunteers' decision making. In two studies which examine the effects of financial incentives and risk of adverse events on healthy volunteers' willingness to participate in research, financial rewards correlate with increased willingness to participate, <sup>29, 30</sup> and aversive treatments correlate

with lower willingness to participate.<sup>30</sup> Bentley and Thacker conclude that even offering high financial rewards did not cause participants to disregard risks.<sup>29</sup> These findings support the results of this review on self-reported motivations.

## **Conclusion and Future Directions**

Although financial reward is the main motivation for healthy volunteers who participate in clinical research that offers them no benefit, other factors clearly influence their decisions. Additional research is needed to examine healthy research volunteers' motivations and decision making processes and to develop best practices for recruitment and use of financial incentives. Examining the ethics of studies involving healthy volunteers and the use of incentives in developing countries is increasingly important, as research involving healthy volunteers expands globally. Further study would also be useful regarding how healthy volunteer motivations vary geographically and among cultures.

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(Empirical Research[mh] OR Clinical Trials as Topic[mh] OR Clinical Trial<sup>23</sup> OR Human Experimentation[mh] OR Biomedical Research[mh])

AND

(Motivation[mh] OR Decision Making[mh] OR characteristic\*[ti] OR why[ti] OR willingness[tiab] OR motiv\*[tw])

AND

(Research Subjects[mh] OR volunteer\*[tw] OR human subject\*[tw] OR healthy subject\*[tiab] OR normal subject\*[tiab] OR participa\*[ti])

Figure 1.

Search terms used in the systematic review of the literature on PubMed

Table 1

Background Information for the Included Studies

Year	Source	n*	Clinical Trial Type	Location/Population	Qualitative/Quantitative	Actual/Hypothetical
2010	Stunkel et al. <sup>24</sup>	138	Phase I bioequivalence study	US drug study participants	Quantitative	Actual
2008	Mtunthama et al. <sup>18</sup>	81	Bronchoscopy studies	Malawi	Qualitative, Quantitative	Actual
2007	Almeida et al. <sup>13</sup>	136	Various Phase I drug studies	Portugal	Quantitative	Actual
2007	Kass et al. <sup>17</sup>	60 (23 employees, 37 community volunteers)	Various clinical research studies	US: University employees and volunteers; all clinical study participants	Qualitative, Quantitative	Actual
1997	Hermann et al. <sup>23</sup>	440	Various pharmacology studies	Germany	Quantitative	Actual
1994	Cunny and Miller <sup>15</sup>	263 (195 participants, 68 nonparticipants)	Clinical drug study	US: Volunteers and university students; both drug study participants and refusers	Quantitative	Hypothetical, Actual
1993	van Gelderen et al. <sup>20</sup>	144 (76% aged 18-30 years, 17% 61 years)	Various studies of food ingredients, lipase inhibitors, enteric coated analgesic and antiphlogistic drugs	The Netherlands	Quantitative	Actual
1990	Bigorra and Baños <sup>14</sup>	319 (250 medical students, 90 experienced healthy volunteers)	Phase I clinical trial	Spain: Medical students and experienced volunteers	Quantitative	Hypothetical, Actual
1990	Vrhovac et al. <sup>21</sup>	97	Various bioequivalence and bioavailability studies	Yugoslavia	Quantitative	Actual
1978	Walsh and Nash <sup>22</sup>	70 (37 inmates who had previously volunteered for phase I drug testing, 33 inmates who had not previously volunteered)	Phase I drug testing	US: Inmates ; some were phase I drug testing participants	Qualitative, Quantitative	Hypothetical
1977	Hassar et al. <sup>16</sup>	79	Phase I and Phase IV clinical drug trials	US: Pharmaceutical employees and university students; all pharmacologic study participants	Quantitative	Actual
1977	Novak et al. <sup>19</sup>	480 (120 students, 120 employees, 120 old inmates, 120 new inmates)	Experimental drug study (administered 4×/day for 10 days with 200 mL total blood drawn)	US: University students, industrial employees, and inmates; some were clinical trial participants	Quantitative	Hypothetical

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Table 2

Motivations of Healthy Volunteers in Included Studies

Year	Source	Study Objective	Study Methods	Payment for the Main Clinical Trial	Most-Reported Motivation
2010	Stunkel et al. <sup>24</sup>	To determine the effect of a shorter consent form on the quality of informed consent	Multiple-choice questionnaire	\$2000	Financial reward
2008	Mtunthama et al. <sup>18</sup>	To determine the usefulness of recruitment and consent information, reasons for participation, and the complication rate of bronchoscopy.	Open question interview with a standard set of questions	Cash value of 50 kg of maize (<\$10)	Access to healthcare
2007	Almeida et al. <sup>13</sup>	To characterize the motivations and attitudes of volunteers and their perceptions of the consent procedure and participation in the study.	Questionnaire in which participants rated items from 0-5	80% of hourly net salary earned in industry and services sector	Financial reward
2007	Kass et al. <sup>17</sup>	To determine whether and how community volunteers differ from employee volunteers in enrollment history, good/bad experiences, and views about who should enroll.	Interview with both open- and closed- ended questions asking if they were "glad" they joined studies and what were the "best things about studies"	various	No clear main incentive
1997	Hermann et al. <sup>23</sup>	To measure the impact of risk on the decision to enroll	Multiple-choice questionnaire	various	Financial reward
1994	Cunny and Miller <sup>15</sup>	To identify motivations and barriers to participation in clinical drug trials.	Multiple-choice questionnaire	various	Financial reward
1993	van Gelderen et al. <sup>20</sup>	To uncover motivations, examine experiences, and evaluate the information provided to healthy volunteers.	Multiple-choice questionnaire	f1600(=\$350) to f12000	Financial reward for young volunteers (<30yo) Access to health care or altruism for older volunteers (>60yo)
1990	Bigorra and Baños <sup>14</sup>	To assess the willingness of medical students to volunteer for clinical trials and to evaluate the weight of the financial reward and other general details as seen by healthy volunteers who had already participated in clinical trials.	Multiple-choice questionnaire	Various (estimated \$45-\$130 per day)	Financial reward
1990	Vrhovac et al. <sup>21</sup>	To analyze the volunteers' occupational distribution, how well they understood the trials they participated in, their opinion about payment and how they weighed the importance of numerous trial elements.	Questionnaire in which participants rated items from 1-5	various	Financial reward
1978	Walsh and Nash <sup>22</sup>	To obtain demographic and motivational data and to determine whether recruiting prisoners for research studies is inherently coercive.	Group interviews followed by a multiple-choice questionnaire	various	Financial reward
1977	Hassar et al. <sup>16</sup>	To learn more about volunteers' motivation and attitudes toward drug studies.	Interview and multiple-choice questionnaire	various	Financial reward
1977	Novak et al. <sup>19</sup>	To compare volunteer rates of different populations and to examine the rationales for their decisions.	Multiple-choice questionnaire	unspecified	To help develop new medicines, financial reward, and to help the sick

#### Table 3

#### Themes

#### Themes

#### **Complex Motivations**

Never was motivation or the decision-making process simple or one-dimensional. Financial reward was usually necessary but never sufficient.

- Motives get people interested in the experiment; optimum information and a personal approach toward the volunteers were important in keeping volunteers motivated.<sup>20</sup>
  - No volunteer considered financial reward unimportant, but 8.8% of volunteers would participate even if there was no financial reward. 13
  - Only 4.2% of medical student volunteers would participate for financial reward alone. 14
  - Financial reward was the primary reason given for volunteering, but the perceived risk was the ultimate deciding factor. 16
- 20.6% denied that financial reward had been their only motive for participation; they stated their other reasons: above all, humanitarian ones.<sup>21</sup>
- Social motives were often a very important secondary motivation.<sup>23</sup>

## Risk

Perceived risk is an important factor, and volunteers expressed an "absolute limit" on risk level:

- $\bullet$  45.6% of nonvolunteers refused because of concerns about the risk involved.  $^{15}$
- Perceived risk of the study was the ultimate deciding factor. 16
- Fear of risk was the main reason for not volunteering (53%). 19

#### Repeat Volunteers

Repeat volunteers were more likely to be motivated by financial reward:

- 90% of repeat volunteers listed financial reward as a primary motivation. 14
- After the first study, university setting volunteers continued to participate for financial reward. 16

#### **Ancillary Care**

In Malawi, access to healthcare was a major motivator. 18

## A Personal Approach

Respecting research volunteers, both by sharing the results of the research and acknowledging competing time commitments, was a motivating factor.

- A personal approach kept volunteers motivated during the experiment. <sup>20</sup>
- $\bullet$  94.9% of volunteers heard about the study by "word-of-mouth".  $^{13}$
- Volunteers wanted access to the results of the research. 18
- The study environment, especially the behavior of the study staff and other volunteers, has a large impact on participant well-being.<sup>23</sup>

<sup>\*</sup> Each bulleted item refers only to a specific study. None are intended to be read as a summary of the data set.

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Table 4

Motivations for Research Participation

Year	Source	Financial Motivators	Altruistic Motivators	Personal Health Motivators	Other Motivators
2010	Stunkel et al. <sup>24</sup>	Financial reward (58%)	None reported.	None reported.	(1)Non-financial (29%) (2)Mixed (13%)
2008	Mtunthama et al. <sup>18</sup>	Financial reward (cash value of 50 kg of maize < \$10) (6%).	None reported.	(1)Access to health assessment (92%). (2)Access to treatment when ill (75%). No subject with good access to healthcare ever joined the study.	Impressed by the goals of the study/ curious about pneumonia (15%).
2007	Almeida et al. <sup>13</sup>	(1)Financial reward ("5" by 58.1% and "4" by 30.1%, "3" by 9.6% and "2" by 2.2%); HOWEVER, 8.8% of participants declared that they would, 52.9% declared that "maybe" they would, agree to participate even if there was no financial reward.  (2)The possibility of a free medical check-up (rated "5" by 20.6% and "4" by 30.9%).	A desire to contribute to the progress of science/medicine (rated "5" by 19.1% and "4" by 27.9%).	The possibility of a free medical check-up (rated "5" by 20.6% and "4" by 30.9%).	Curiosity (rated "5" by 8.1% and "4" by 27.2%).
2007	Kass et al. <sup>17</sup>	(1)Financial reward (55% said money was a good aspect, 46% said money was the best aspect). (2)An easy way of life/ easy way to make money (22%).	Helping others or contributing to a larger purpose (48%).	Learning about their health, science, or medicine, received physical exam or had problems detected such as high cholesterol or hypertension.	Meeting people (57%).
1997	Hermann et al. <sup>23</sup>	Financial reward (53.3%)	(1)Contribution to an improvement of pharmacotherapy (27.8%) (2)Social Responsibility (12.7%)	None reported.	Other (6.2%)
1994	Cunny and Miller <sup>15</sup>	Financial reward (85.1% of participants; 92.6% of nonparticipants).	(1)Contribution to the health of others (44.1% of participants, 44.1% of nonparticipants). (2)Contribution to the scientific knowledge regarding medications (44.1% of participants, 51.5% of nonparticipants).	Improvement of own health (47.2% of participants).	None reported.
1993	van Gelderen et al. <sup>20</sup>	Financial reward (f1600–\$350-f12000) (65%; 96% of 18-30 y.o. volunteers).	For the benefit of others (83% of the volunteers who cited this were $> 61$ y.o.).	To get a medical check-up (75% of the volunteers who cited this were $> 60$ y.o.).	None reported.
1990	Bigorra and Baños <sup>14</sup>	Financial reward –4.2% of medical students would participate for financial reward alone; –32.2% of medical students would participate for a combination of both scientific interest and financial reward. –90% of experienced volunteers participated for financial reward.	None reported.	None reported.	(1)Scientific interest –24.7% of medical students would participate for scientific interest alone; –32.2% of medical students would participate for a combination of both scientific interest and financial reward. (2)Curiosity (6.3% of experienced volunteers.)

Year	Source	Financial Motivators	Altruistic Motivators	Personal Health Motivators	Other Motivators
1990	Vrhovac et al. <sup>21</sup>	Financial remuneration (cited as an exclusive motivator by 78,4%, cited as a non-exclusive motivator by 20.6%).	(1)Humanitarian reasons (Most of the 20.6% who did not cite financial remuneration as an exclusive motivator). (2)Anticipated contribution of the drug to the medicine and the society (average rating of 3.30 out of 5, with 5 being the highest).	None reported.	None reported.
1978	Walsh and Nash <sup>22</sup>	Money (81% of volunteers, 52% of nonvolunteers).	(1)To help people (70% of volunteers, 61% of nonvolunteers). (2)To do something important (51% of volunteers, 46% of nonvolunteers).	None reported.	(1)To break the monotony of prison routine (49% of volunteers, 52% of nonvolunteers). (2)Friends participate (11% of volunteers, 6% of nonvolunteers). (3)To feel closer to outside society (8% of volunteers, 9% of nonvolunteers).
1977	Hassar et al. <sup>16</sup>	Financial remuneration (91% university setting, 89% pharmaceutical setting).	Contributing (48% university setting, 67% pharmaceutical setting).	None reported.	(1)Curiosity (33% university setting, 15% pharmaceutical setting). (2)Professional interest (0% university setting, 26% pharmaceutical setting).
1977	Novak et al. <sup>19</sup>	(1)Financial remuneration (57%) (2)Present unemployment (8%).	(1)To develop new medicine (69%). (2)To help the sick (56%). (3)To help society (11%).	(1)To help own health (35%). (2)To obtain free medical exams (22%).	(1)The desire to participate in something important (43%). (2)Curiosity (25%). (3)To break monotony (8%). (4)My friend participates (5%).

\* All ratings in this row on a scale of 0 to 5, with 0 signifying "no importance" and 5 signifying "extreme importance.